

8. Parent Presentations about Developmental Disabilities

Parent Presentations about Developmental Disabilities

Occasional lecture presentations by parent- or patient-advisors can add a human dimension to didactic material. The presentations described here address developmental disabilities with a slide show and question-and-answer session by parents. The parents translate diagnostic criteria into challenges and experiences from their children's lives, while students or residents ask questions of the parents as they seek to understand the realities of life with a disability. Parents share pictures of their children and provide stories about their children at home, in the community, and at school. Learners acquire information about developmental disabilities and hear about the implications of special needs in the lives of children and families, with parents' reflections about how physicians can help address needs.

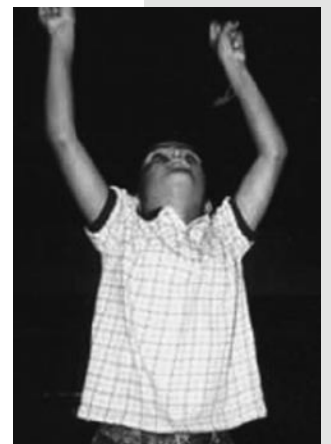
Goals

1. To introduce students to DSM-IV criteria for the diagnosis of developmental disabilities in children.
2. To introduce students to the stories of children and families who live with developmental disabilities.
3. To give students an opportunity to ask questions of parents of children with developmental disabilities.
4. To help students begin to think about what physicians can do to help children with developmental disabilities and their families.

Objectives

Medical students or residents will:

1. Cite DSM-IV criteria for diagnosis of specific developmental disorders.
2. Formulate questions for parents about the broad context of life for their children with developmental disabilities and articulate these questions in a question/answer session with a parent.
3. Delineate specific ways that developmental disabilities manifest at home, at school, or in the community.
4. Describe helpful ways for physicians to interact with families with children with developmental disabilities and/or link them with appropriate assistance.



Description of the Activity

For medical students, this activity occurs in an existing course on human development or another course that covers childhood developmental disabilities and it correlates with didactic content from that course and textbook. For example, the Uniformed Services University includes a course in the second year of the medical school curriculum entitled *Human Behavior and Development*. The course director makes an effort to involve people with various developmental or psychiatric diagnoses in the lectures for this course, so the involvement of parents of children with special needs as lecturers complements the course director's goals. The syllabus describes the course in this way:

"The Human Behavior Course provides lectures and small group discussions in normal human development and psychopathology. The first segment of the course focuses on psychological growth and development from infancy to adulthood. The second segment introduces major psychiatric disorders and emphasizes biological, psychosocial, and social factors in diagnosing and treating these disorders. The four small group sessions held throughout the course emphasize learning objectives through case discussions and are intended to provide clinical correlations to lecture materials."¹

The objectives for the section on learning disorders read as follows:

1. Know the "gestalt DSM criteria" for each of the basic disorders covered in this lecture.
2. Know relevant/current neurobiological theory relating to these disorders.
3. Describe basic risk factors, prognostic factors, and epidemiology of each disorder.
4. Know basic treatments for each disorder.

"Students gain a sense of the 'big picture' and realize that this is more than just a disease or a mental disorder."

—Charles Engel, parent-advisor and Human Behavior Course Director

In general, medical students can gain information about DSM criteria, neurobiological theory, epidemiology, and treatment from textbooks and literature reviews, and residents may have acquired this content from reading or lectures in their past. However, both medical students and residents will benefit from the human story that accompanies learning disorders. One effective way to provide this is to invite parents to tell their own stories, accompanied by pictures of their children and families engaged in the activities of life. When the stories are coupled with the opportunity to participate in a frank question/answer session with parents, learners gain a perspective about the way a developmental disability manifests in the lives of parents and their children. It is difficult for students or residents to gain a meaningful understanding of

8. Parent Presentations about Developmental Disabilities

the human struggles that accompany living with disability by reading books or listening to didactic lectures by content experts. The best way to gain this dimension is through in-person time with people who live with disability every day. For example, a textbook might state that parenting a child with a learning disability requires parents to fill different roles or that rearing a child with a disability places stress on marriage relationships. One parent told the story of his child's early years, diagnoses, and struggles in school and then said,

“Parents find themselves in a place they couldn't begin to imagine at the beginning of their relationship or when they first became parents. A child with special needs or learning differences places a parent in a role never anticipated when entering a marriage, a role of being an advocate for a child in a society that neither understands the child's needs nor knows how to address them. Physicians seek to provide therapy for the child and bring healing, but when not all of the child's needs are cured the parent is left to advocate in an educational system unable to bend to meet the needs of those who learn differently. Laws passed to provide access to education for everyone haven't created educational systems that meet the needs of those who learn differently, and the advocate is left to struggle. The parent remains bound to the child and in need of help and healing from both physicians and educators.”

—*Brian King, parent-advisor*

Hearing such a story and then entering a conversation with probing questions about the stresses and challenges of parenting a child with a disability will convey depth far beyond the textbook.



Typical Questions from Learners

- How has your child's disability affected his or her siblings?
- How has your child's disability affected your marriage?
- What is the hardest thing for you as this child's parent?
- What do you think your child will do when he or she grows up?
- What have doctors done to help you meet your child's special needs?

Preparing Parent-Advisors to Present a Lecture

"They [the students] asked good questions. Hard questions, but questions that needed to be asked and addressed. I told them, 'nothing is sacred.' I believe in honesty as the only way to get information out and in the open."

—a parent-advisor

While parents have powerful human stories to share about their children, most parents do not have experience presenting before large groups. Sometimes the preparation that has become second-nature for faculty who lecture frequently needs to be made explicit for a parent. An hour or two spent conversing on the phone and exchanging drafts of presentations and photographs through email provides parents with the technical assistance that will enable them to craft a framework that will communicate effectively to medical students or residents. So while these steps of preparation may seem obvious, they can be useful as a checklist

to explicitly convey practical steps to parents.

Preparation for the presentation includes the following steps:

1. Identify parents of children with developmental disabilities who are comfortable speaking and answering questions before a large group.
2. Talk with each parent about his or her child. Ask questions like the following:
 - Tell me about your child.
 - When did you first notice your child's special needs?
 - How does your child interact with others in your family?
 - How does your child do in school?
 - What does your child do for fun?
 - In what activities does your child participate in the community?
 - What is especially challenging in your child's life?
 - What is especially rewarding about parenting your child?
 - What would you want medical students, residents, and doctors to know about your child and the ways they can help you, your child, and others with similar needs?
3. Ask the parents to find pictures of their children at several ages, and to write some simple descriptions of their children at these different ages.
4. Assemble the pictures and descriptions in a slide presentation. Some parents may want to do this themselves, while others may want to provide pictures and oral descriptions and have a faculty member assemble them into a presentation.

8. Parent Presentations about Developmental Disabilities

5. Locate the DSM-IV criteria for diagnosis of each child's special needs. Add them to the beginning of the slide show.
6. Discuss with the parents the types of questions the students or residents may ask after the presentation and how they might respond.

A sample presentation appears at the end of this chapter. This presentation introduces two children and provides the material needed for a lecture period of an hour to an hour and a half, including question/answer discussion with two parents. During the presentation, the faculty member's role is minimal: facilitate the flow of the session from the didactic presentation of diagnostic criteria to the parent presentation and question/answer time with students, and ensure that the presentation and discussion fit into the allotted time.

Presentation Outline

Developmental Disabilities

- I. Learning Disorders
 - A. DSM-IV definitions for reading disorder and attention deficit/hyperactivity disorder—faculty
 - B. Putting a face on learning disabilities—parent presentation
 - C. Questions/answer discussion with the parent
- II. Autism
 - A. DSM-IV definitions for autistic spectrum disorder—faculty
 - B. Putting a face on autism—parent presentation
 - C. Question/answer discussion with the parent
- III. Conclusion—Faculty—What does this mean for doctors and families and children?
 1. Identifying and referring
 2. Medical diagnostics
 3. Advocates needed
 4. Special education and community services

The Role of Patient- and Family-Advisors

Parents tell the stories about their children with more reality, poignance, and detail than a faculty member without experience as the parent of a child with special needs could ever accomplish. Parents' straight-forward sincerity and willingness to share their experiences and insights help students or residents remember why it is important to listen, understand how diagnostic criteria translate into real-life challenges, and see why understanding the human dimension of diagnoses will help them relate to families and meet their needs more effectively. One parent-presenter speaks about her son in this way:



Jacob at 6: "Getting By—Or Is He?"

"It's difficult to know if things are 'getting better.' There are days when it seems as if, no matter how hard you try, they are not better and perhaps even worse. But shortly after that something miraculous happens and you know that you have made a difference. There's no cookie cutter method for achieving success, but a continuous dialog with his teachers and school administrators is essential to that success."

and then, Jacob at 8: "More Meetings."

"At the end of 2nd grade we had a meeting to discuss what 3rd grade would look like for Jacob. Would he still need special ed services??"

Would math suddenly become a problem because of all the reading comprehension it required??? Who decided? Me? Them?? What if we chose poorly??? In the end we decided one more year of special ed services would probably be a good thing. But would he be able to keep up with the other kids when 4th grade came along? We don't know the answer to that one yet, but we keep meeting and talking and adjusting. The meetings are a good thing. No decision is made in a vacuum that way. The school couldn't choose the best solution without input from home and I couldn't begin to guess how to fix things without them."

—Lori Irving, parent-advisor

These illustrations and comments from the heart of a mother, and those quoted earlier from a father, spoken in person and followed by conversation with students, convey the meaning of attention deficit-hyperactivity disorder in a way an objective presentation of didactic information could not accomplish.

When parents and medical students or residents interact in this way, the students or residents also see that parents are capable partners in observing, learning, and sharing co-

8. *Parent Presentations about Developmental Disabilities*

gent information about their children, their children's diagnoses, and treatment. At the same time, parents gain a glimpse of medical education with its many demands. Each gains appreciation for the other and understanding furthers mutual respect.

Appreciation for Parent Presenters

Thank you so much for sharing with medical students about your children and their experiences with school, medical care, and life. Your stories are so real and powerful, and you are so insightful about your children's needs. You provide a tremendous addition to medical education when these students hear about real people living real lives with children who happen to have special diagnoses. You provided a level of learning that the students can't acquire from books or even from experiences in clinics and hospitals, by sharing pictures and events and hopes and worries about your children. Thank you.

Reference:

- I. Engel C. Human Behavior Course, Department of Psychiatry, Uniformed Services University of the Health Sciences. Available at <http://cim.usuhs.mil/ps02001>. Accessed March 2, 2005.

